DOCUMENT RESUME

ED 213 188 EC 141 139

AUTHOR	Koerber, Pat, Ed.
TITLE	Conference Report on the National Conference for Parents of the Handicapped (1st, Indianapolis, Indiana, October 17-19, 1980).
INSTITUTION	Parent Information Resource Council, Inc., Indianapolis, IN.
PUB DATE	80
NOTE	60p.
EDRS PRICE	MF01/PC03 Plus Postage.
DESCRIPTORS	Child Advocacy; *Disabilities; Elementary Secondary Education; Legal Problems; Nutrition; Parent Associations; Parent Attitudes; *Parent Conferences; *Parent Role; Parent Workshops

ABSTRACT

The first National Conference for Parents of the Handicapped (Indianapolis, Indiana, 1980) is summarized. Contents of 11 workshop presentations are described, including parents' roles as advocates, parental concerns, the influence of diet on behavior, genetics, in home respite care, legal issues, and parent coalitions and organizations. An evaluation/summary chart is presented along with names and addresses of conference participants. Among appended information are the minutes of the conference's Committee of the Whole. (CL)

****
* Reproductions supplied by EDRS are the best that can be made *
* from the original document. *
****

U.S. DEPARTMENT OF EDUCATION
NATIONAL INSTITUTE OF EDUCATION
EDUCATIONAL RESOURCES INFORMATION CENTER (ERIC)
☐ This document has been reproduced as received from the person or organization originating it.
☐ Minor changes have been made to improve reproduction quality.
• Points of view or opinions stated in this document do not necessarily represent official NIE position or policy.

CONFERENCE REPORT ON THE FIRST NATIONAL CONFERENCE FOR PARENTS OF THE HANDICAPPED

Held October 17 - 19, 1980
at the Marten House, Indianapolis, Ind.

PAT KOERBER, Ed.

"PERMISSION TO REPRODUCE THIS MATERIAL HAS BEEN GRANTED BY
Rita A. Cloud
TO THE EDUCATIONAL RESOURCES INFORMATION CENTER (ERIC)."

Sponsored by
Parent Information Resource Council, Inc.
222 East 70th Street
Indianapolis, Indiana 46220

In cooperation with
Parent Information Resource Center
1363 East 38th Street
Indianapolis, Indiana 46205
(317) 926-4142

TABLE OF CONTENTS

	Page
Introduction	1
Conference Summary and Up-Date	2
Summaries of Workshop Presentations	
Advocacy (Dorothy McNair, Ruth Sullivan)	6
Closer Look (Marie Ormsby)	9
Diet and Behavior (Laura Stevens)	10
Genetics (Drs. Sam Rhine and Joe Christian)	13
In-Home Respite Care (Betty Oliver)	14
Barry Neil and Suzi Kaufman	16
Legal Issues (David Dunlap)	17
P.A.C.E.R. (Virginia Richardson)	19
Parent Organizations (Betsy Britten)	21
Pilot Parent (Patty McGill Smith)	23
V.I.A. (Betty Hourihan)	25
Evaluation	28
Name and Addresses of Conferees	31
Appendix	38

CONFERENCE REPORT

INTRODUCTION

This conference report has been prepared by the Parent Information Resource Council, Inc. to give those who attended the conference and other interested parties an overview both of the planning process and the conference itself. The Council hopes it will renew pleasant memories of those who took part and be of use to others who are planning similar conferences.

The appendix contains copies of flyers, form letters and programs that were used in the project.

Deep gratitude and appreciation go to all who helped make this First National Conference for Parents of the Handicapped a success and paved the way for future conferences. Special mention must be made of the following, for without their contribution and cooperation there would have been no conference:

The Indianapolis Foundation, which made the conference a reality with grants for both the planning period and the conference
The Rock Island Refining Corporation, Western Electric Company and CMW, Inc., which also made financial contributions to the project
The Pioneers of Western Electric Company
The National Conference Advisory Board
The conference presenters
The Parent Information Resource Council, Inc., board* and members
The Parent Information Resource Center and Advisory Board
Dr. Kathleen Nitsch who served as consultant for the conference and Dr. Robert Flynn who assisted Dr. Nitsch in the priority setting section of the conference.

*Parent Information Resource Council, Inc., Board Members - October 1980

1. G. Elizabeth Kenny, Learning Diabilities - President
2. Beverly Purdue, Autism - Vice President
3. Alice Ryan, Cerebral Palsy - Secretary
4. Ruth Jarvis, Aphasia - Treasurer
5. Sally Baxter, Spina Bifida
6. Evelyn Froehlich, Downs Syndrome
7. Georgianna Garlock, Cerebral Palsy
8. Joan Hermeling, Learning Disabilities
9. Marty Meyer, Cerebral Allergy
10. Patricia O'Drobinak, Cerebral Palsy
11. Mary Pease, Hearing Impaired

CONFERENCE SUMMARY and UP-DATE

October 19-21, 1980, the first National Conference for Parents of the Handicapped was convened in Indianapolis by the Parent Information Resource Council, Inc. It had been preceded by a year-long planning process in which parents and parent groups were contacted nationwide for input.

The first conference mailing was a flyer sent in 1979 and early 1980 to organizations and individuals surveying their interest in, and seeking suggestions for, a national conference. A letter detailing the main objectives of the conference was then sent to those who had expressed an interest. Conference objectives were: 1) communication among parents from broad geographic and disability areas and 2) development of the beginning of a national parent information network to enable parents to stay in communication with each other. Recipients were requested to return the tear-off at the bottom of the letter to request brochures and list other parents who would like an invitation. From the beginning, great effort was made to identify and contact parent leadership across the country and organize the conference for such a leadership group.

When tear-offs, flyers and other correspondence from parents were received, information was compiled on program interests and outstanding parent leaders. These leaders were then contacted by members of a special Council committee requesting them to serve on a National Conference Advisory Board (NCAB). Those who accepted became an integral part of the conference as presenters and as leaders in sessions held to develop a national parent information network.

Once the NCAB was in place and the Council had completed program plans, conference invitations with pre-registration forms were mailed - and finally the conference was ready and guests began arriving.

Georgianna Garlock of the Council was in charge of registration and was greatly assisted by the Pioneers of Western Electric Company under the capable direction of De ette Bennett, and by Council members. The Pioneers also assisted in pre-conference mailings and other tasks.

The conference was officially opened at 7:30 p.m. by Frank Kenny, husband of Council president G. Elizabeth Kenny, and three members of the Parent Panel: Ruth Christ Sullivan, director, the Autistic Services Center, Huntington, West Virginia; Dorothy McNair, parent advocate and educator from Eugene, Oregon; and Betty Hourihan, director, the Volunteer Information Agency, Quincy, Massachusetts.

Eleanor Owen, of the Washington Advocates for the Mentally Ill and board member of the National Alliance for the Mentally Ill, Seattle, Washington, was unable to be on the panel or give her presentation on Community Support Programs because of last minute illness.

Following the panel presentation, Dr. Kathleen Nitsch of the Indiana University, Purdue University in Indianapolis Department of Psychology asked participants to list activities they considered important for both an effective local group and national parent network. She and her colleague, Dr. Robert Flynn, worked around the clock prioritizing the information. Their findings for the national network are included in the appendix.

Saturday, until dinner, was taken up with workshops, summaries of which follow this section.

Consequently, at dinner Saturday evening leaders of the groups and other NCAB members decided to convene all interested conferees in a Committee of the Whole. This committee met twice, Saturday night and Sunday morning. It was chaired by Pat Koerber and a planning process developed by Lois Rood and Lyn Rucker of Nebraska was used by the group under the tutelage of Patty Smith of Omaha. Bonnie Fairchild, President of the International Association of Parents of the Deaf, Wilmington, Delaware, served as secretary. Minutes of the meetings are included in the appendix.

The Committee of the Whole resolved:

to form a system of support to assist the families and friends of persons with handicaps or disabilities;

that there is no coordinated system and that the current system is fragmented and ineffective;

and that there should be a national system for coordinating:

1. dissemination of appropriate, current information
2. promotion and encouragement of advocacy
3. development of linkage among parent groups

The committee then selected a Steering Committee with representatives from each of the ten federal regions, two members at large and Pat Koerber as chairman. Ten local contact persons were also selected and matched with a regional representative to act on behalf of that representative when necessary. The conference adjourned at noon Sunday, leaving the Steering Committee with the task of development of purpose and structure for a network.

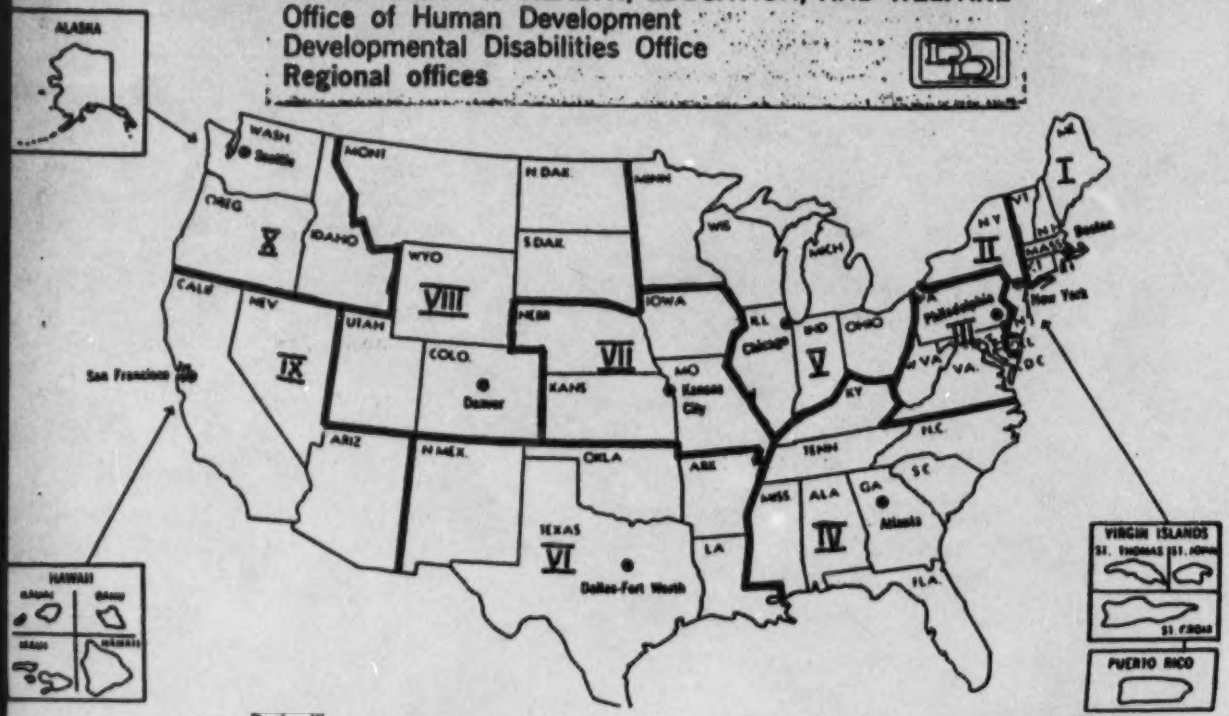
In view of the charge of the Committee of the Whole, local contacts met at the Parent Information Resource Center (PIRC) in Indianapolis on February 22 to plan a meeting of the Steering Committee to be held at PIRC April 24 to 26.

Steering Committee members and local contacts convened this meeting at 7:30 Friday evening, April 24. The agenda was concerned with purpose, structure, programs, funding and evaluation of a national network and minutes are in the appendix.

The meeting did result in the formation of the "Parent Network: The national communication system to link parents of those with special needs." Steering Committee members became members of the board. Local contacts will serve for at least one more year to assist the board in planning, decision making and setting up the next conference. A list of board members and contacts follows.

A second national conference is planned for the spring of 1982 in Omaha, Nebraska. At that time by-laws for the Parent Network will be distributed.

DEPARTMENT OF HEALTH, EDUCATION, AND WELFARE
Office of Human Development
Developmental Disabilities Office
Regional offices



Region I
JF. Kennedy Bldg.
oston, Mass. 02203

egion II
6 Federal Plaza
ew York, NY 10007

Region III
PO Box 13716
36 & Market Sts
Philadelphia, Penna. 19101

Region IV
50 Seventh St, NE
Atlanta, Ga. 30323

Region V
300 S. Wacker Dr.
Chicago, Ill. 60607

Region VI
1114 Commerce St.
Dallas, Texas 75201

Region VII
601 E. 12th St.
Kansas City, Mo. 64106

Region VIII
9017 Federal Office Bldg.
19th & Stout Sts.
Denver, Colo. 80202

Region IX
Federal Office Bldg.
50 Fulton St.
San Francisco, Calif. 94102

Region X
Arcade Bldg.
1321 Second Ave.
Seattle, Wash. 98101

PARENT NETWORK BOARD MEMBERS		Local Contacts
Region I	Betty Hourihan (617) 692-2282 WAYS & MEANS 105 Randolph Avenue Milton, Massachusetts 02187	Martha Meyer (317) 447-5261 7 Wildwood Drive Lafayette, IN 47905
Region II	Bonnie Fairchild (302) 654-1330 208 Brecks Lane Wilmington, Delaware 19807	Rita Cloud (317) 638-7409 1334 Olive Indianapolis, IN 46203
Region III		Rosemarie Palermo (219) 322-1017 2016 Robin Holld Blvd. Schererville, IN 46375
Region IV		Lucinda Dillahay (317) 636-8531 810 N. Tacoma Indianapolis, IN 46201
Region V	Deborah Wetzel (513) 574-8427 5367 San Rio Courts Cincinnati, Ohio 45239	Susan Schill (317) 897-2444 9719 East 17th Street Indianapolis, IN 46229
Region VI	Betty Oliver (504) 733-2744 P.O. Box 511 Westwego, Louisiana 70094	Lowell Barker (219) 665-7284 R.R. 2, Box 183E Angola, IN 46703

Steering Committee Representatives		Local Contacts	
Region VII	Patty McGill Smith (402) 553-7060 44 South 44th Street Omaha, Nebraska 68106	Sally Hamburg (219) 289-9363 1922 Briar Way South Bend, IN 46617	
Region VIII	Elaine Clearfield (303) 333-7266 310 South Jersey Street Denver, Colorado 80224	Evelyn Froehlich (317) 283-499 3819 Delaware Indianapolis, IN 46205	
Region IX	Betsy Trombino (602) 863-4048 121 E. Voltaire Avenue Phoenix, Arizona 85022	Teresa Torres (219) 942-1426 4416 16th Street Hobart, IN 46342	
Region X	Dorothy McNair (503) 342-4250 2207 Wellina Drive Eugene, Oregon 97401	Cheryll McAtee (317) 482-4017 820 Cohen Street, Lot 79 Lebanon, IN 46052	
At Large	Kook C. Huber (317) 299-6499 4909 Manning Road Indianapolis, IN 46208		
	Pat Koerber (317) 253-5708 5538 N. Pennsylvania Street Indianapolis, IN 46220		

SUMMARIES OF WORKSHOP PRESENTATIONS

ADVOCACY

Dorothy McNair and Ruth Sullivan

"Parents working together can accomplish what one parent working alone cannot," stressed Dorothy McNair, mother of three handicapped sons, ages 28, 27 and 21. She made several points in her discussion of advocacy. One, she emphasized that as parents we must learn to work with professionals. Next she advised that parents band together and demand needed services. Examples of such cooperation included her going to the Red Cross asking for a swimming instructor for handicapped children using a pool in a backyard and, in another instance, asking for a teacher to be provided locally to give mobility instruction to blind students. These were eventually accomplished with the State of Oregon assuming financial responsibility even though this was before the advent of Public Law 94-142.

Dorothy now trains parents in Oregon concerning their legal rights under the law and the availability of services, with heavy emphasis on Individualized Education Plan (IEP) training. This enables trained parents to attend IEP meetings with other parents who need help. She advises parents to use the IEP as a communication tool to get services needed by their child and to work with their child's teacher as closely as possible. Parents must know the 94-142 law and their rights under this law. Go through channels (principal, special education director, school board) to form advisory boards made up of parents of handicapped children and publicize your efforts. Parents must be ready to present facts to school boards and not emotionalism. Be as calm and objective as possible. In another area of activity, Dorothy is working on a HUD grant to gain housing for physically handicapped adults.

Ruth Sullivan, parent of a teenage autistic son, started by saying that one doesn't need a lot of professional education to be an advocate, just a lot of persistence. This is the most important quality of advocating. She went on to say that legislators are the "parents" of the state and when approaching them, parents must be assertive and demand equality for their handicapped children rather than asking for charity. Remember that legislators are elected officials and are there to work for all.

Again, parents must be well informed as to laws regarding the handicapped. Advocacy groups should put out newsletters keeping members in touch with each other and condensing local laws to keep their members informed.

She mentioned that in the Vocational Rehabilitation Act there are

three services that are always available to parents at no cost, regardless of income: 1) Evaluation Services, including a medical evaluation, 2) Counseling, and 3) Job Placement. She stressed that parents should find out what is available in their states at no cost.

When approaching professionals to ask for services, try to educate them to your point of view and know your rights. Threaten legal action as a last resort as this is a long and expensive process. On the other hand, parents should not forget teachers have rights also. They have the right to refuse to perform certain services if they have had no training, for example, catheterisation. Teachers have the right to equal participation in the IEP conference. They have the right to teach under professional standards of practice. Finally, teachers have the right to serve their children and not just the system.

Ruth gave examples of what national and state advocacy groups can accomplish. In Washington, D.C., the National Society for Autistic Children recently succeeded in geting Autism removed from the "Severely Emotionally Disturbed" category in the special education law. She stated that parents are the life-long advocates for their children. One good thing for an advocacy group to do is to give awards publicly to professionals who have been of special help to them.

She asked what the outstanding problem was in Indiana. The answer was a great lack in providing related services to school children. Dorothy McNair mentioned that it's always good to find other children who need the same type of services and ask for them as a group. Ruth pointed out that all related services should be listed in each child's IEP. Be very specific in writing the goals and objectives in the IEP. Also, the related-service provider should be at the IEP meeting if at all possible. Try to get other parents to come to the IEP meeting for support, if there is difficulty. If the school officials use the excuse of "no money," find out what the school is providing for non-handicapped children in the way of services and equipment. If cooperation and/or satisfaction cannot be gained from the local school corporation, contact the state special education director with the complaints. Again, be very specific. An official complaint may also be filed in writing, with the Office of Civil Rights (Cleveland is the Regional Office for Indiana).

Questions were then asked about mainstreaming. Ruth again stated that if mainstreaming is requested by the parents, this should be written into the IEP. If the child is in a special school and cannot be mainstreamed, then another placement should be requested.

If the IEP is not being implemented, a parent can write the special education director of the state with a complaint. Ruth advised keeping a notebook for recording all letters, phone calls, dates, what was said, etc.

Dorothy McNair finished the workshop by stating that parents of handicapped children should always think of themselves as "professionals" as they have more valuable information to provide about their child than anyone else.

Summarized by Beverly Purdue

CLOSER LOOK WORKSHOP

Marie Ormsby

In opening the workshop, Marie Ormsby, Project manager for Closer Look, asked the group, "What are your concerns as parents of handicapped children?" Some of the major concerns addressed were:

Career and vocational opportunities. Vocational education is a coming field for the handicapped. It was brought out that the vocational education fund has ten percent of its monies set aside for the special needs of the handicapped. Each federal dollar should be matched on the state and local level. This money should be used for adaptive equipment or whatever may be needed to make existing programs suitable for the handicapped. It is not necessary to set up completely separate programs.

There should be consumer representation on the vocational education boards according to law. On the federal level, this is sometimes interpreted to mean the local vocational education teacher, when in reality it should be an actual consumer.

Recognizing the realistic potential of my child. It is very difficult for a parent to know when to stop pushing and pulling the child and yet to motivate him to his fullest potential.

Parent-professional relationships. There is a need for improved parent credibility and parent participation. There is much concern on the part of the parents in how to deal with intimidation. Knowing your rights and speaking out sometimes works. Going to the media to drum up support sometimes works, but is a rather drastic measure to have to take.

Summarized by Pat O'Drobinak

DIET AND BEHAVIOR

Laura Stevens, presentor

Laura Stevens is the parent of two sons who have severe allergies and is author of How to Feed Your Hyperactive Child and How to Improve Your Child's Behavior Through Diet.

The first part of the workshop Laura related experiences with her sons, Jack age 9, and Jeff age 6, and how diet control changed the lives of the family. Jack was born prematurely ending a stressful pregnancy, a common denominator for many allergenic children. He had a very difficult infancy and early childhood with hyperactivity, behavior problems, speech and motor difficulties. There were years of hospitalization, consulting physicians, testing, ritalin, with no improvement. It was difficult to get physicians to realize the child had a physical rather than a psychological problem.

Finally they tried the Feingold diet which eliminates artificial colors and flavors and foods with salicylate. Within days, Jack's behavior had changed dramatically. For the first time he felt good about himself, was calm and responsive, showed affection, dressed himself and made eye contact with people.

Laura then realized other foods were also bothering him and took him to a pediatrician in Fort Wayne, Indiana, who does special allergy testing and treatment for hyperactive children. Testing revealed Jack, and later Jeff and Laura, are universally allergic and must carefully manage their diet and environment.

Jack is now in the fourth grade, a superior student, with no learning disabilities or behavior problems and his motor coordination is improved. He is all right unless the allergy treatment program and diet are broken, then he reverts to his former behavior.

The younger son, Jeff, had different problems but they stemmed from the same cause, allergies. He also was premature but was a sleepy, lethargic child with pyloric stenosis and allergies. Speech was delayed and severe behavior problems with compulsive, repetitive and destructive activity developed.

He was given allergy treatment and diet and he is now in first grade with good academic development. Speech is still behind but all other development is normal.

Two observations were made about the effects of allergies on the boys. One is that allergy to various foods cause very specific behaviors. For example, allergy to one food caused Jeff to repeatedly

hit his brother. When the food was eliminated, so was the behavior spontaneously stopped. The second thing noted is that when the allergy-causing food is returned to the diet, the former behavior pattern also returns. Jeff, for example, can lose his speech when subjected to certain foods.

The second part of the workshop dealt with the general aspects of food allergies and their treatment. Slides of food sensitive children portrayed how allergies could be detected in their appearance. They tended to look tired, have puffy eyes with dark circles and pale complexions. Physical symptoms include leg and joint aches, headaches, stomach aches, a Dr. Jekyll/Mr. Hyde syndrome of personality changes. They may be either extremely overactive or underactive. Bedwetting and frequent colds are often problems along with ear infections. Many will have more traditional forms of allergy such as asthma, hay fever and eczema. These latter are readily recognized by the medical profession. What is not generally recognized is that allergies can affect any system in the body and also the brain in what is called cerebral allergy.

Persons are inclined to become sensitive to the things they eat most. Testing for allergies is done several ways. Foods the child craves or ones he especially avoids both are suspect. A diet diary is kept that records all food eaten and the behavior exhibited. A person may consult a clinical ecologist (there are six in Indiana, about 400 nationwide) who are physicians trained to discover what in the environment is making one ill. Those with allergies can also be bothered by such things as pollen, molds and dust. Symptoms may be worse in one season than another. Some are chemically sensitive to such things as gas fumes, tobacco, chlorine in swimming pools, chalk, ink, perfumes, pesticide, etc.

A medical examination includes looking for physical symptoms, provocative food testing and testing for inhalants. These are done by using an extract of the suspect substance. For children it is put under the tongue; for adults an injection is made under the skin, then behavior is watched along with a weal where an injection is made. Provocative food testing is expensive because of the time involved. It can take hours.

Treatment includes avoidance of substances that cause allergies, use of a rotation diet in which food eaten one day is not eaten again for four days. The concept is that this lessens the body's exposure to foods and allows time for recovery.

Vitamins and minerals are another part of the regimen. Vitamin shots can be done at home and are inexpensive. Antihistimines are used at times. Also, exercise on a regular basis is important.

A blood test, Rast, can be done for inhalants and food allergies. It measures the level of antibodies in the body in response to the challenge substance. It is expensive and not always reliable.

To diagnose allergies, the Randolph Ecological Unit in Zion, Illinois, has patients fast for five days with nothing but spring water, then foods are returned, one at a time, to the diet. There are three or four clinics in the country doing this.

Hypoglycemia may go along with allergies and some think it is a form of allergy. Others with allergies may have an absorption problem. Although they ingest large amounts of vitamins and minerals, they may still have deficiencies if their bodies cannot make use of the nutrients. Many in the medical profession are becoming interested in the field of allergies because of sensitivity in family members of personal allergies. However, many other physicians are not trained in this area nor are they open to the concept of allergies.

There are a number of books on the subject of allergies in children. Laura Stevens books give some background material in addition to menus and recipes. A reading list she has compiled is available from the Parent Information Resource Center.

Summarized by Pat Koerber

GENETICS

Dr. Sam Rhine & Dr. Joe Christian

An informational seminar on genetics was presented by Sam Rhine, a geneticist with the Marion County Association for Retarded Citizens.

"The Most Important Nine Months of Your Life" informed parents about various causes of birth defects. Down's Syndrome was discussed at length, and the use of slides simplified showing the two types of chromosomal defect (extra 21st chromosome and chromosomes that break and become attached to others. The "breaking" problem can be genetically transmitted.) Phenylketonuria (PKU) was a defect used to explain gene abnormalities. Rhine demonstrated by using a string of pearls, each pearl representing a gene attached to a chromosome (50,000 in each cell in the body.) "Odds," or genetic ratios, of having a child with a gene-related defect were discussed. Finally, developmental birth defects were addressed. These are unexplained problems that develop while the fetus is within the womb.

Dr. Rhine is a superb instructor who simplified genetics in order for each parent to better understand human development. The slides enhanced his message of the importance in genetic counseling and steps that can be taken to prevent needless birth defects (i.e. rubella immunization; infant screening; nutrition; consumption of alcohol and use of drugs; etc.)

Rhine is enthusiastic about the future as genetics is still a science in its infancy. He primed parents to expect the possibility of surgery on a fetus yet within the womb; the discovery of more gene-related metabolic disorders and treatments to assure a normal life; new drugs to prevent premature births.

Dr. Joe Christian, Chairman of the Indiana University Department of Medical Genetics, was present at the workshop with Dr. Sam Rhine for the question and answer period.

Parents left this seminar wiser about the science of genetics and excited about the future.

Summarized by Marty Meyer

IN-HOME RESPITE CARE

Betty Oliver

Presenting the In-Home Respite Care was Betty Oliver, Westwego, Louisiana. She organized the Association for Research in Children's Emotional Disorders (ARCED) and developed and received funding for its In-Home Respite Care service. She served two years as parent coordinator for the P.T.A., has worked with and helped organize various state and local parent groups and is a member of the Huxley Institute and the National Alliance for the Mentally Ill. Her experiences as a parent appear in her book, The ABC's of Hanging on While Raising a Family with a Disturbed Child.

In her excellent presentation she showed a practical, step-by-step guide to setting up a respite care service in the community. The process included incorporating an organization, sponsoring such an undertaking, applying for a grant, developing a program, recruiting trainees, training, and obtaining employment for those trained.

One of the highlights of the workshop was the method of training the caregivers. Recruits were 18 years of age or older and included college students interested in going into medicine, interested family members or their friends, persons who were retired. After recruitment and an interview, those chosen were ones who had a kind personality, enjoyed going to the home and having regular hours and who were willing to take the necessary training.

The training was provided by different agencies, such as the American Red Cross (for CPR and first aid), agencies for the blind, deaf and autistic, educational sources, the local Association for Retarded Citizens and cerebral palsy clinics. The training was six weeks or 100 hours. American Rental Supply House set up the hospital equipment to use for training. Space and a telephone were provided by a church. Books and appropriate toys that could be taken with them when caregivers cared for the handicapped person were made by volunteers. Tape recorders were also supplied to record stories, songs, etc.

The caregivers were awarded certificates upon completion of training and became individual contractors with the parties involved. The ARCED supervised the program, but the details were determined by the caregiver signing a contract with the parents or guardians. For a minimum of four hours, fees of $3.35 an hour plus gas or busfare were charged. Overnight costs were $35; short weekend (9:00 a.m. Saturday to 6:00 p.m. Sunday) was $80 and a long weekend (3:00 p.m. Friday to 6:00 p.m. Sunday) was $110.

The more people involved, the better the program. Broad support

increases visibility of the program, hence greater community awareness, more research into handicapping conditions, etc. Support persons are also important to the project to exchange information, and provide psychological uplift for those doing the actual respite care.

Summarized by Evelyn Froehlich

WORKSHOP

Barry and Suzi Kaufman

The Kaufmans were greeted by a "standing-room-only" group of parents. They presented a brief discussion as to the "Options Process," Mr. Kaufman's subject for the keynote luncheon address. However, more emphasis was placed on certain segments or "steps" within this Process. The Kaufmans spent little time talking, as parents were anxious to ask questions. Most of these centered on two Process steps, which are "total acceptance of the child's disability" and working in reaching a child with "no stated goal/time framework." Most parents had reservations in using these particular steps, citing "burn-out," work responsibilities, fear their child would become completely dependent and undisciplined. The Kaufmans answered each parent's question thoughtfully, stressing openness in giving love.

Suzi Kaufman fielded questions about family responsibility to other children and how to go about involving them -- a reaching out to the handicapped/disabled sibling without resentment (again, the total acceptance, the mainstay of the "Options Process").

A brief discussion was presented about a young autistic child from Mexico. The Kaufmans counseled with the parents and began working with this child, using the same methods as with Raun, their son whose story is told in their book Son-Rise. Frustrations and setbacks were openly analyzed. (A book about this experience has just been published, A Miracle To Believe In.)

Parents had easy access to the Kaufmans after this session and many talked with them in depth about their own situations.

Summarized by Marty Meyer

LEGAL ISSUES

David Dunlap, LLB

The challenge in the legal community is to make it apparent to the judiciary that we are not talking about what society owes the handicapped or what society ought to do to or for them, but we are talking about what the handicapped have a right to expect as citizens. This is a principle we should never lose sight of.

It is imperative that we understand we are talking about the handicapped and their right to the opportunity to develop whatever potential they have; their right to access to whatever public means are available to the rest of us and to exercise those opportunities. What the law is really all about is what sort of accommodations are necessary for the rest of society to make so that those rights can be exercised.

The judiciary is having difficulty grasping the concepts of 94-142 and Section 504. There is failure to recognize that we are talking about the opportunity to develop. Each individual has a different developmental continuum. It is society's responsibility to help each one along that continuum at his or her own pace and to stimulate that pace to the best of professional ability. Because the point that may be reached for one is not as far down the road of the developmental continuum as for others doesn't change society's duty to provide the service. If the means to the end of that development are greater than they are for the rest of us it is still necessary to provide that level of support.

94-142 talks about equal opportunity; not equal services and not equal dollars. It has to do with the right to an equal opportunity to benefit from public education.

In considering rights, we are talking about the continuum of education at one end and residential services on the other end. As in the case of education, the reason for residential services is habilitation. The handicapped have a right to work and live as normally as possible and to exercise their capacities, whatever they are; and government has to begin to accommodate them. If we are successful in integration on the educational level, but don't create a system that will accommodate them when they are adults, we are in trouble.

It is felt that groups such as the Association for Retarded Citizens are providing services that are the responsibility of government. Government needs to be better prepared to support these types of services. We, as parents and advocates, need to be better prepared to support these types of services. We need to keep working on these problems to get the country to recognize it as the responsibility of government to provide these services.

Of great concern is the fact that the average lawyer doesn't understand this area of the law. Parents need to provide lawyers with information and help them understand the needs of the handicapped. Every lawyer on the block needs to be exposed to these problems. We are the only people who are going to make the real objectives of the legal process for the benefit of handicapped people known.

The approach to obtain residential services needs to be a bit different. The legal rights for habilitation have only been set forth in one federal district court. We don't have a legal hammer to insure accommodation in the community. If we think there should be one, now is the time to approach the governmental community to let them know there is a need and it is going to increase as our population lives longer. In preaching deinstitutionalization, we need to be careful that the quality of service does not deteriorate. Some legal foot holes can be found for this. For example, if federal dollars are used for groups homes, etc., they cannot replace state dollars.

A guideline for habilitation can be that there is a duty to provide some level of services if the freedom or liberties of an individual are restricted by confinement in a state institution. If no crime has been committed, there must be a reason for confinement, and thus a reason for habilitation. The issue of the limit of government responsibility must also be resolved.

Summarized by Georgianna Garloch

P.A.C.E.R.

Virginia Richardson

Virginia Richardson of the Minnesota P.A.C.E.R. (Parent Advocate Coalition for Educational Rights) reminds us that so many parents of handicapped or disabled children struggle greatly with feelings of helplessness whenever they must deal with school systems, vocational education systems, etc. "I just never knew I (or my child) had any rights," or "We felt very defeated," are common remarks. Mrs. Richardson urges us to be very alert, to seek information and methods from helpful professionals and parents. Information may include assertiveness training and techniques (learning to ask for and find services in a positive, effective manner) understanding and utilizing laws (P.L. 94-142, Section 504), and organizing parents and other concerned citizens to advise and seek necessary means to better provide a quality education and life for our children.

Informing and teaching parents provides the important firm foundation of effectiveness for reaching out and educating the community and society. Handicap Awareness programs such as The Kids on the Block (a group of delightful muppets, some handicapped - some non-handicapped) help teach and overcome fears and unconscious prejudices concerning our disabled youngsters. Teaching society to look at our child first as just another "kid" regardless of the handicap is one of our greatest challenges. Mrs. Richardson remarks that "The Kids" have been used widely and well throughout Minnesota classrooms and communities. She further comments that... "many parents are very afraid of mainstreaming (integration into regular classrooms) not because of the education, but of how the other children will react to their child in the classroom." "The Kids" does much to help raise consciousness about the truth that children with handicaps have the same needs for love, growth and development that all children require.

Mrs. Richardson also explains that in other related areas: school testing, IEP's, etc., parents must remain alert to their responsibilities. She states that too often school testing doesn't always give an accurate picture of the total child. Tests show more what is wrong with the child than what is right with the child. A total assessment of children includes information gathered from the school staff and the parents. Working together to determine the program that will best teach and challenge our youngsters is the function of the Case Conference. Mrs. Richardson goes on to say that parents have the right to examine all school records and have an even greater responsibility to keep good, written records of their own about their child's history. She tells us to remember that these written records are truly invaluable and should contain information about previous evaluations, hospital and health records, happenings at school, promises given (what was said and who said it), growth and development changes (speech, tasks mastered, etc.). She emphasizes that records help the parent have a more valid picture of their child's development and potential - which is usually greater than we perceive.

Mrs. Richardson says that the IEP conference should give specific direction to the child's program. It must not become just the intention to do "good things." "Many times parents go to the conference and are presented an IEP to sign - and they sign it automatically. Parents should help develop their child's program and see that it includes the child's strengths and weaknesses - things to build on. Parents have this valuable information and it must be carefully planned." She explains that the IEP should answer four important questions: 1) Does the IEP communicate - are they able to understand it? 2) Is it a basic of teaching - something that can be used for the teacher to teach? 3) Can it be measured? 4. Is it relevant to my child?

Finally, she comments that the strength of the Minnesota Coalition has depended on respect for other people and the knowledge that we all struggle with complex questions that have no easy answers. Most important, P.A.C.E.R. encourages everyone to be well informed about the issues at hand and take responsibility for what needs to be done. Be prepared. Have the information before you need it.

Summarized by Pat Higginbotham

PARENT ORGANIZATIONS

Betsy Britten

Betsy Britten is the mother of three teenage daughters, one with spina bifida and one with schizophrenia. Through her work as a mother, she has become the director of the Parent Infomation Center in Cincinnati, which is a service of twelve different groups of parents of the handicapped. Originally, she organized, at the urging of physicians, a group of parents of children with spina bifida who were being served by the Children's Hospital in Cincinnati. She is presently on the board of the National Spina Bifida organization and believes strongly in the power of parent groups.

From her broad experience in working in organizations, she has found that the same principles apply regardless of whether a parent group or a coalition is being developed. The first question to ask is, why organize? If the purpose is not clear, don't do it. She also urged cooperation with professionals because they can do things parents cannot do. However, she insisted that parents must stay in charge and retain control over their children.

Betsy's workshop used audience participation in a process for problem solving applied to the difficulties of parent organizations and coalitions. Members of the audience introduced themselves and told about their children and the parent groups to which they belonged. A number of parents were either involved in starting new cross-disability groups or coalitions.

Two problems were pointed out concerning such organizations. One, a member must confront and deal with the reality that the purpose of the group may be in direct opposition to what he wants. Second, competition for funding and tax money can arise among parent groups serving different disabilities or in a coalition. There is not always a common denominator in dealing with the needs of children with various handicaps and parents must realize that there will be different, even competing, interests, and plan for such eventualities.

A coalition presents even more difficulty than organizing a parent group and those involved must be able to look ahead, Betsy stressed, at the needs of all children, not just all handicapped children, but all children. A parent must believe his child will benefit by serving all children.

A participant pointed out that a purpose of a coalition is to work together on issues of common interest and in no way dilute efforts of individual disability groups. After all, children who are physically disabled, mentally handicapped or emotionally disturbed are more alike than unlike each other. In addition, working in coalitions has

another benefit of making members more knowledgeable and sophisticated about handicapping conditions and needs thus preparing them better to attend board meetings, and serve on boards of schools and public agencies.

The audience then listed seven problems of coalitions and divided into small groups to discuss them. They were:

the possibility that some voices may not be heard
geographic limitations
clear definition of purpose
establishment of personal and group priorities
burn-out of both leaders and members
out-reach effectiveness and increasing membership
leadership problems

Group reports followed although time did not allow for all groups to be heard. Group I noted that when there is a conflicting opinion in a group, a sub-group may be formed. Concerning definition of purpose, another group emphasized that it may be better to begin with a small, attainable purpose and that it is important to identify issues of interest to the majority. Funding also may be vital, especially to reimburse volunteers and pay for newsletter costs.

Work with parents is based on two beliefs, Betsy said. One is an abiding belief in the value of the unique knowledge every parent has about his child. The other is the abiding belief in the capacity of each parent to be an effective case manager and advocate for the child.

Summarized by Pat Koerber

PILOT PARENT PROGRAM

Patty McGill Smith

Patty introduced herself as the parent of a 10-year-old daughter whose disability was not discernible at birth. The family was one-child focused in those days, and it was an experience of "relief" when the child's disability was given a "name." The importance of having someone to provide positive feedback was shared along with the positive results achieved through good services and parent support. It is important for parents and professionals to work together. Patty's child progressed from an initial diagnosis of severely retarded - through moderately retarded - to now functioning in the mildly retarded range and reading at the third grade level.

The Pilot Parent Program (PPP) actually is a program of parents helping parents which began with the mother of a Down's Syndrome child. In 1970 the program was initially sponsored by the local Association for Retarded Citizens (A.R.C.) with the belief that parent-to-parent help cannot be left to "chance," that effort must be made to find those parents needing help. It takes a long time to win the confidence of the community, but referrals are now common from doctors.

Training for parents who "Pilot" involves a screening process to identify those who can do this work, who have gone beyond the needs of their own child, and who have the time to devote without receiving public honors. The Omaha program now has over 40 active parents and more than half of those were originally "piloted," i.e., receiving the help. Those parents are now public speakers, school district representatives, serve on different boards and represent many disabilities. Until 1974 the program was sponsored by the A.R.C. and served only parents of the retarded, but major changes have been made to include all handicaps. This represented a challenge to break down the prejudices that existed - mostly from the leadership of the various organizations.

PPP has learned that the parents' stories are always the same. The kids are different - but the parents are the same. A Pilot Parent must be able to relate to the pain of the new parent. There are three questions which are always asked; 1) how long a time to get a diagnosis? 2) how long before you met another parent of a handicapped child? 3) how long to secure services? Training involves six three-hour sessions. Pilot Parents brings people together to learn from each others, and its message is to love and enjoy your child, and to treat him as a growing and learning person regardless of the handicap.

For a two-year period (1977-79) federal funds were available to set up PPP's in a four-state area: Iowa, Nebraska, Kansas and Missouri. There are now 35 different programs. A few have paid coordinators, but most are strictly voluntary. The voluntary programs have a lot going

for them because funding comes and goes; professionals come and go; but parents stay - and PPP is totally a parents' program. In addition to the program for new parents, there is a need among the parents of teenagers and adults - both those living at home and those who are institutionalized.

When PPP held its national meeting, there were 17 states represented. The programs don't happen without huge difficulties. Successes must be shared and lessons learned from others' experiences. It is important for the parents and professionals to work together. Originally two out of three who started this work were professionals, and professionals still work with parents during the training phase.

One goal of parents should be to become the child's best advocate while living the message of the Serenity Prayer: Acceptance/Courage/ Wisdom.

Summarized by Ruth Jarvis

VIA

Betty Hourihan

Betty Hourihan explained how VIA (Volunteer Information Agency) was born out of her own frustration as a parent in getting help for her special needs child. She began by gathering ten women from different groups in the South Shore of Boston and presenting to them the need that existed for an information and referral agency. These women agreed to help. They held coffee hours with speakers on topics of general interest and charged $2 per person. Over 100 women participated. This raised some money, but more important they asked those interested in helping to sign up. They had 35 to 40 women who were interested. Since then they have gotten hundreds of volunteers - it has become the "in" thing to do.

One of the first things VIA did was an information survey in conjunction with the South Shore Mental Health Center. They surveyed facilities and services available in the community and this became the backbone of their filing system. They developed a library. They surveyed doctors and dentists to determine their interest in serving the special needs child and then passed this information on to parents.

VIA has volunteers who help in many ways. Some help in the office answering the phone, some do surveys of available services, some are coop drivers, some are fundraisers, etc. There are enough volunteers so that each can come in one morning a month. The volunteers are trained carefully. They are compassionate and caring. VIA has found that people are anxious to do work with their minds that is challenging and they try to place the volunteers where they will feel rewarded.

Some of the volunteers are good fundraisers and enjoy doing this. They hold tennis tournaments, fashion shows, brunches, bargain buses (buses that go to factory outlets), etc.

At first VIA was part of the South Shore Mental Health Center, but in order to keep their independence, they incorporated. This has given them the opportunity to do some things they wouldn't have been able to do as an affiliate of a governmental agency.

Some of the activities that VIA is doing are:

Providing information and referral.
Holding a swim program for special needs children.
Providing a respite care program for parents who never get a chance to get away. Special needs teachers volunteer their time and are given a cash gift in return. Parents are comfortable with this arrangement.

VIA also has several publications.

A. One publication explains what VIA is and where it is. It also gives the phone number to call.

B. Another publication is called Now's a Good Time for Counseling. This explains to parents that they are in charge of their lives and that counseling is an effective way to KEEP in good shape. It also gives the phone number of VIA.

C. There Is Something Special About You is a pamphlet aimed at brothers and sisters of special needs children. It brings to the minds of the parents the fact that they must be aware that the siblings of special needs children often need help too.

D. God and Jimmy is a pamphlet that explains about what it means to be a friend of a special needs child. It tells about the VIA Club. There is also available a VIA Club kit with instructions on how to set up a VIA Club, including press releases, awards, etc.

Understanding Handicaps is a VIA program in the schools. It is aimed at fourth graders, which is the age group when prejudices and fears grow and is the time to sensitize. Film clips are used and the handicapped go into the schools to help present the program. One week's program concerns the blind, the next week the deaf, the next concerns physical handicaps and another week the mentally retarded. It is hoped that the children will take home what they have learned and share it with their parents.

Special needs parents are a cross section of America. We should not let ourselves be intimidated. Our outlook should be nice, intelligent and informed. In dealing with professionals we should be role models. Reflect the way you'd like to be treated.

Parents feel comfortable in calling VIA because the name is non-labeling. A parent who calls VIA is reaching out for help for her child and VIA is there to provide that help.

Summarized by Pat Higginbotham

EVALUATION

EVALUATION

In obtaining a grant from the Indianapolis Foundation to sponsor the national conference, two objectives were set and evaluation of the project was to be based on their accomplishment: 1) conference participation, and 2) establishment of the nucleus of a permanent national parent information network.

I. Conference Participation

Approximately 135 persons attended the conference with twelve states represented. No tabulation of disability interests was made, but informal observation showed that some were: allergies, amputees, autism, birth defects, cerebral palsy, Downs syndrome and other genetic disorders, emotional disturbance, epilepsy, hearing impairment, learning disabilities, mental retardation, Prader-Willi syndrome, schizophrenia, spina bifida and visual impairment.

On the following page is a graph showing how participants rated the conference on the conference evaluation form. Comments made on the form indicated that conferees were equally divided between finding the parent-to-parent contact and the presentations most valuable. Most workshops were cited as most "helpful" to at least one participant, but the Kaufman and genetic presentations proved most popular.

Everyone completing an evaluation form voted for another national conference and many suggestions were made concerning it. High on the list were stipends to enable more parents to attend such conferences and more time for informal sharing. Other requests were: exhibits of adaptive equipment; more workshops on diagnosis, treatment and research; more professionals to hear the parent viewpoint and interact with parents (although there was a request for a conference for parents only); a workshop by a handicapped adult; some attention given to the needs of parents of young adults who have not had the advantages of good services and are now mentally ill in addition to their original handicap. Adverse comments focused on cancellation of workshops, lack of promptness in beginning and ending workshops and noise from other rooms. Working sessions were nominated as least helpful by some. However, the evaluations were generally enthusiastic and several voted it the best conference they had ever attended.

II. Formation of a National Parent Network

Conference participation in the formation of the national network reflected the disability and geographic distribution described in I. Through working sessions (which were not successful) and two meetings of the Committee of the Whole, the nucleus of a national network was

developed before the conference adjourned on Sunday. The purpose of such a network was outlined and a steering committee and local contacts were selected to carry on the task of organization once the conference was over.

Since then, there have been numerous communications among the steering committee members and local contacts in addition to one meeting of local contacts and a steering committee meeting.

At the steering committee meeting (which also included local contacts of members both present and absent), the Parent Network was established, a board and officers elected with the charge of seeking incorporation, committees appointed, and a second conference planned for the spring of 1982 (in Omaha, Nebraska). The first Network newsletter is scheduled to be distributed at that time. Minutes of the meetings of the Committee of the Whole and steering committee are in the appendix.

EVALUATION FORM SUMMARY

NATIONAL CONFERENCE FOR PARENTS OF THE HANDICAPPED

October 17-19, 1981

	Agree			Disagree	
	5	4	3	2	1
1. Generally, the conference met my expectations	47%	39%	8%	3%	3%
2. The general session and workshops were relevant	42%	50%	8%		
3. The workshop sessions provided new information for me	55%	31%	11%	3%	
4. Overall, the conference was well organized	57%	30%	10%	3%	
5. Overall, the presentors were prepared	58%	36%	3%		3%
6. Overall, presentors were responsive to participants	71%	16%	8%	5%	
7. Overall, I felt free to discuss and ask questions	63%	28%	3%	6%	
8. The materials provided were appropriate	72%	22%	6%		
9. The facilities were comfortable	84%	16%			
10. I had adequate time to interact with other participants	37%	31%	29%		3%

NATIONAL CONFERENCE FOR PARENTS OF THE HANDICAPPED & DISABLED

Lita D. Aldridge
College Hall Gallaudet College
7th & Florida Ave.
Washington, D.C. 20002
(202) 651-5046

Lowell & Sarah Barker
R.R. 2, Box 183E
Angola, Indiana 46703
(219) 665- 7284

Mary Anne Barry
6739 N. Newgard Ave.
Chicago, Ill. 60626
(312) 761-8468

Sally Baxter
323 W. 81st Street
Indianapolis, IN 46260
(317) 257-3617

De ette M. Bennett
1922 Glenridge Drive
Indianapolis, IN 46218
(317) 357-3890 Home
(317) 352-2417 Office

Judi Hill
815 Elmwood Circle
Noblesville, IN 46060
(317) 773-2843

Nora E. Billadeau
9330 Idlewild Drive
Highland, IN 46322
(219) 924-1976

Tom & Ruby Bontreger
10766 CR 16
Middlebury, IN 46540
(219) 825-2647

Susan Brewer
1518 Franklin St.
Lafayette, IN 47905
(317) 742-8206

Elizabeth Britten
SOC Parent Information Center
3024 Burnet Ave.
Cincinnati, Ohio 45219
(513) 861-2400

Roger Brunkow
4526 Miller Drive
Lafayette, IN 47905
(317) 589-3913

Loraine Buchanan
c/o Multiple Handicapped Program
621 W. Madrone
Roseburg, Oregon 97470
(503) 440-4794

Linda Campbell
3525 E. 71st Street
Indianapolis, IN 46220
(317) 255-1168 or 255-5973

Marilyn Casper
135 Sunnybrook Ct.
South Bend, IN 46637
(219) 272-8832

Judy Cass
1408 Logan Street
Noblesville, IN 46060
(317) 773-3946

Joe Christian, Ph.D., M.D.
I.U. Dept. of Medical Genetics
Riley Hospital, Room 129
1100 West Michigan
Indianapolis, IN 46202
(317) 264-2241

Rita Cloud
1334 Olive Street
Indianapolis, IN 46203
(317) 638-7409

Carol Cooper, Exec. Director
UCP of Central Indiana
615 N. Alabama
Indianapolis, IN 46204
(317) 632-3561

Joenell Crisp
4927 Carvel Avenue
Indianapolis, IN 46205
(317) 257-6974

Devon & Joanne Davis
705 Delamatyr
Knox, IN 46534
(219) 772-3816

Grace Demoss
4917 W. 25th Street
Indianapolis, IN 46224
(317) 244-4586

Lucinda Dillahay
810 N. Tacoma
Indianapolis, IN 46201
(317) 636-8531

Treva E. Dorrell
19 N. Dequincy
Indianapolis, IN 46201
(317) 357-1573

John & Gloria Doyen
1919 Jackson Street
Portage, IN 46368
(219) 762-1941

David Dunlap
151 N. Delaware Street
Indianapolis, IN 46204
(317) 634-9052

Dorothy Endres
13815 N. Meridian
Carmel, IN 46032
(317) 846-6036

Bonnie Fairchild
International Association of the Deaf
208 Brecks Lane
Wilmington, Delaware 19807
(302) 654-1330

Carol Fischer
19 N. Dequincy
Indianapolis, IN 46201
(317) 357-1573

Tricia Fleckenstein
630 Queenswood Drive
Indianapolis, IN 46217
(317) 882-8687

Robert Flynn, Ph.D.
Psychology Dept., IUPUI
KB 44C
Indianapolis, IN 46205
(317) 923-1321 (Ext. 266)

Betty Foster
555 Sunset Boulevard
Greenwood, IN 46142
(317) 881-3966

Gayle Foy
8812 Dunsmuir Drive
Indianapolis, IN 46260
(317) 846-6457

Connie Freeman
1209 Rochester Street
Lafayette, IN 47905
(317) 474-9491

Evelyn & Ralph Froehlich
3819 N. Delaware Street
Indianapolis, IN 46205
(317) 283-4991

Roberta Gajewski
1501 Friendship Drive
Indianapolis, IN 46217
(317) 888-7171

Georgianna Garloch
6015 Alton Avenue
Indianapolis, IN 46208
(317) 293-3245

Paula Goldberg
Pacer Center
4701 Chicago Avenue, S.
Minneapolis, Minn. 55419
(612) 827-2966

Mary Ellen Graham
7220 Algonquin Drive
Cincinnati, Ohio
(513) 271-6481

Joy Hague
4127 Otterbein Avenue
Indianapolis, IN 46227
(317) 788-0539

Sally Hamburg
812 E. Jefferson
South Bend, IN 46617
(219) 234-7101

Ruthann Harp
7614 Woodside Drive
Indianapolis, IN 46260
(317) 253-9625

Lavonne Heighway
655 Valley View
Zionsville, IN 46077
(317) 297-3990 Office
(317) 873-2163 Home

Joan Hermeling
5628 Ashurst Street
Indianapolis, IN 46220
(317) 251-4295

Doris Hickerson
1550 Cliftwood Drive
Clarksville, IN 47130
(812) 945-4806

Patricia Higginbotham
9852 E. Troy Avenue
Indianapolis, IN 46239
(317) 862-3952

Judith C. Houk
1200 E. 42nd Street
School for the Deaf
Indianapolis, IN 46205
(317) 924-4374 Ext. 121

Betty Hourihan
VIA-77 Parkingway
Quincy, Massachusetts 02169
(617) 773-9525

John E. & Kook C. Huber
4909 Manning Road
Indianapolis, IN 46208
(317) 299-6499

Mary Ann Hussey
12010 Gray Road
Carmel, IN 46032
(317) 844-9378

Ruth Jarvis
2750 S. Kenyon Drive
Indianapolis, IN 46203
(317) 359-9080

Nora Juday
11103 Moss Drive
Carmel, IN 46032
(317) 844-2324

Barry Neil & Suzi Kaufman
46 Shelter Lane
Roslyn Heights, New York 11577

Beverly Keilman
9604 Walnut Drive
Munster, IN 46321
(219) 924-0302

Frank & Gerri Kenny
4412 Briarwood Drive
Indianapolis, IN 46250
(317) 849-2169

William & Lura Kill
1921 Lawrence Avenue
Indianapolis, IN 46227
(317) 783-2594 Home
(317) 639-8524 Office

Leonard & Pat Koerber
5538 N. Pennsylvania
Indianapolis, IN 46220
(317) 253-5708

Muriel LaDuke
1775 N. Audubon
New Albany, IN 47150

Betty & Robert Leak
R.R. 1, Box 123A
Lizton, IN 46149
(317) 994-5966

Meredith Luckenbill
6065 Gladden Drive
Indianapolis, IN 46220
(317) 251-6936

Ethel E. Mace
3530 Forest Manor
Indianapolis, IN 46218
(317) 545-8231

Janet Macon (Multiple Handicapped Program)
621 W. Madrone
Roseburg, Oregon 97470
(503) 440-4794

Marissa Sison Manlove
2101 Ohio Boulevard
Terre Haute, IN
(812) 232-6608

Cheryil & Mark McAtee
1031 Schleicher Avenue
Indianapolis, IN 46229
(317) 899-5569

Oma McDonald
1051 Elmwood
Noblesville, IN 46060
(317) 773-6008

Martha McDonough
216 Carter Avenue
Clarksville, IN 47130
(812) 282-1755

Dorothy McNair
2207 Wellina Drive
Eugene, Oregon 97401

Marty Meyer
7 Wildwood Drive
Lafayette, IN 47905
(317) 447-5261

Wendy Michalski
6332 Whitehaven, Apt. 1228
Indianapolis, IN 46254
(317) 299-0706

Evelyn Middelstadt
1902 Chicago #72
Valparaiso, IN 46383
(219) 464-5033

Shari Miller
4927 Carvel Avenue
Indianapolis, IN 46205
(317) 257-6974

Shirley J. Miller
11422 Creekwood Circle
Indianapolis, IN 46239
(317) 894-8190

Michael Morton
Dept. of Mental Health
5156 Rosslyn Avenue
Indianapolis, IN 46205
(317) 257-9013

Kathleen Nitsch, Ph.D.
5343 N. Park Avenue
Indianapolis, IN 46220
(317) 251-5828

Theda Nixon
812 E. Jefferson
South Bend, IN
(219) 234-7101

Pat O'Drobinak
222 E. 70th
Indianapolis, IN 46220
(317) 257-1851

Betty Oliver
P.O. Box 511
Westwego, Louisiana 70094
(504) 341-5811

Marie Ormsby
"Closer Look"
1201 16th St., N.W.
Washington, D.C. 20036
(202) 833-4160

Eleanor Owen
906 E. Shelby
Seattle, Washington 98102

Rosemarie Palermo
2016 Robin Hood Blvd.
Schererville, IN 46375
(219) 885-7429
(219) 322-1017

Judy Parkinson
1308 Hoover Lane
Indianapolis, IN 46260
(317) 255-2270

Beverly Purdue
6035 Forest View Drive
Indianapolis, IN 46208
(317) 253-1821

Joanne Queenan
PIC
2975 Libra Lane
Cincinnati, Ohio 45239
(513) 861-2400 Office
(513) 522-5137 Home

Sam Rhine
C/O MCARC
2400 N. Tibbs
Indianapolis, IN 46222
(317) 639-6271

Virginia Richardson
4044 Oakland Avenue South
Minneapolis, Minnesota 55407
(612) 827-2966

Donna E. Rolston
1815-3 Fox Point Trail
Ft. Wayne, IN 46816
(219) 447-7313

Susan & Wendy Rudolph
3604 Royal Oak
Muncie, IN
(317) 282-3778

Les & Alice Ryan
5346 N. New Jersey Street
Indianapolis, IN 46220
(317) 257-3644

Susan Schill
9719 E. 17th Street
Indianapolis, IN 46229
(317) 897-2444

Jennifer Seet
9402 E. 82nd Street
Indianapolis, IN 46256
(317) 849-2517

Rose D. Sison
2101 Ohio Boulevard
Terre Haute, IN
(812) 232-6608

Jane M. Smith
308 N. High
LaGrange, IN 46761
(219) 463-2618

Patricia McGill Smith
444 S. 44th Street
Omaha, Nebraska 68131
(402) 541-7606

Laura Stevens
1111 Eton Street
West Lafayette, IN 47906
(317) 463-1292

Ruth Sullivan
101 Richmond Street
Huntington, West Virginia 25702
(304) 523-8269

Paula Taylor
2541 Meadowmar Lane
PIC
Cincinnati, Ohio
(513) 861-2400 Office
(513) 231-0732 Home

Teresa L. Torres
4416 16th Street
Hobart, IN 46342
(219) 942-1426

Diana Vento
10833 Timberlane
Carmel, IN 46032
(317) 846-8678

David L. Walker
417 Meadowview Ct.
Carmel, IN 46032
(317) 844-8832

Mary Ruth Wehmeier
1601 E. 77th Street
Indianapolis, IN 46240
(317) 257-6087

Robert & Nancy Woods
Greentown, IN

Connie Woodbury
PIC
7209 Virginia Avenue
Cincinnati, Ohio
(513) 861-2400 Office
(513) 793-8196 Home

Donna Youkilis
2752 Losantiridge
PIC
Cincinnati, Ohio 45213
(513) 731-0840

Gail Young
1007 Black Oak Drive
Roseburg, Oregon 97470
(503) 440-4794

Organization Addresses

Autism Services Center
306 31st Street
Huntington, West Virginia 25702
(304) 523-8269

Closer Look
Parents' Campaign for Handicapped
Children and Youth
1201 16th Street, N.W.
Washington, D.C. 20036
(202) 833-4160

Gallaudet College
7th and Florida Streets
Washington, D.C. 20002
(202) 651-5046

Indiana School for the Deaf
1200 East 42nd Street
Indianapolis, IN 46205
(317) 924-4374

Indiana University Medical Center
Department of Medical Genetics
Riley Hospital for Children, Room 129
1100 West Michigan Street
Indianapolis, IN 46202
(317) 264-2241

International Association of
Parents of the Deaf
208 Brecks Lane
Wilmington, Delaware 19807
(302) 654-1330

Marion County Association for
Retarded Citizens
2400 N. Tibbs
Indianapolis, IN 46222
(317) 639-6271

P.A.C.E.R. Center
4701 Chicago Avenue, South
Minneapolis, Minn. 55419
(612) 827-2966

Parent Information Resource Center
1363 East 38th Street
Indianapolis, IN 46205
(317) 926-4142

Parent Information Resource Council, Inc
222 East 70th Street
Indianapolis, IN 46220
(317) 862-3952

Pilot Parent Program
3212 Dodge Street
Omaha, Nebraska 68131
Fran Porter
(402) 348-9220

Southwestern Ohio Coalition for
Handicapped Children
Parent Information Center
3024 Burnet Avenue
Cincinnati, Ohio 45219
(513) 861-2400

Task Force on Education for
the Handicapped
Parent Information Center
812 East Jefferson Street
South Bend, IN 46617
(219) 234-7101

United Cerebral Palsy of
Central Indiana
615 North Alabama Street
Indianapolis, IN 46204
(317) 632-3561

Volunteer Information Agency (VIA)
77 Parkingway
Quincy, Massachusetts 02169
(617) 773-9525

APPENDIX

MINUTES

COMMITTEE OF THE WHOLE

NATIONAL CONFERENCE FOR PARENTS OF THE HANDICAPPED AND DISABLED

At the National Conference for Parents of the Handicapped and Disabled, a committee of the whole convened at the Marten House, Indianapolis, Indiana on October 18, 1980, at 8:30 p.m. The meeting was chaired by Pat Koerber and Patricia McGill Smith presented a review of the planning process as developed by Lois Rood of the University of Nebraska Medical Center and Lynn Rucker, executive director of Region V of Mental Retardation Services of Nebraska. Bonnie Fairchild took notes.

Using the planning phases presented by Patty Smith, the committee of the whole resolved:

to form a system of support to assist the families and friends of persons with handicaps or disabilities;

that there is no coordinated system and that the current system is fragmented and ineffective;

and that there should be a national system for coordinating:

1. dissemination of appropriate, current information
2. promotion and encouragement of advocacy
3. development of linkage among parent groups.

The meeting adjourned at 10:05 p.m., to be reconvened the following morning.

A committee of the whole convened at the Marten House at 9:30 a.m., October 19, 1980.

It was decided to develop a system to meet the identified need for a national coordinated parent information network mechanism.

After extensive discussion it was decided to select only parents of persons with handicaps to do the steering committee work.

A steering committee of ten regional representatives, two members-at-large and Pat Koerber as chairman were selected. Kook Huber accepted as an at-large member and Barbara Scheiber will be contacted to serve as an at-large member.

Marie Ormsby was elected as technical advisor, subject to approval of the board of the Parents Campaign for Handicapped Children and Youth, with a local contact to be Mary Ann Barry.

The steering committee representatives were selected from the ten national

regions as follows:

I. Boston - Betty Hourihan
II. New York -
III. Philadelphia - Bonnie Fairchild
IV. Atlanta -
V. Chicago - Virginia Richardson (subject to her approval)
VI. Dallas - Betty Oliver
VII. Kansas City - Patty McGill Smith
VIII. Denver -
IX. San Francisco -
X. Seattle -

The national steering committee will consult with ten local contact persons to formulate a working paper outlining the structure and system to meet the purpose of the National Parent Network and will report back to those in attendance at the 1980 Indianapolis National Conference for Parents of the Handicapped and Disabled. The ten local contacts and the region representatives with which they will work are:

1. Pat Higginbotham - Betty Hourihan
2. Rita Cloud - Bonnie Fairchild
3. Lowell Barker - Betty Oliver
4. Sally Hamburg - Patty McGill Smith
5. Cheryil McAtee - Dorothy McNair

Local contacts to be assigned:

1. Betsy Britten (subject to her approval)
2. Carol Fischer
3. Rosemarie Palermo
4. Susan Schill
5. Teresa Torres

Local contacts were selected from the Indiana/Ohio area who live in proximity to each and are able to do the physical committee work of the steering committee in consultation with the regional representatives. The meetings of local contacts will be open to anyone in the area.

National Parent Network
Steering Committee Meeting
April 24-26, 1981
Indianapolis, Indiana

Members Present:

Region I	Martha Meyer, local contact
Region II	Rita Cloud, local contact
Region III	
Region IV	Cindy Dillahay, local contact
Region V	Susan Schill, local contact
Region VI	Betty Oliver, Louisiana
	Sarah & Lowell Barker, local contacts
Region VII	Patty Smith, Nebraska
	Marilyn Casper & Theda Nixon, local contacts
Region VIII	Elaine Clearfield, Colorado
Region IX	Betsy Trombino, Arizona
Region X	Dorothy McNair, Oregon
At-large	Kook Huber
Chairman	Pat Koerber

Friday, April 24, 1981

The meeting was chaired by Pat Koerber. The committee decided that local contacts would have voting rights only if the regional representative was absent. Vacancies on the Steering Committee will be discussed on Sunday; members will be asked to submit names for consideration. Pat Koerber will serve as the second at-large member of the committee, bringing the total number to 12. We discussed a possible contact with Candlelighters, a support group for parents of children with cancer.

In working on a purpose for the network, it was decided to develop a philosophy statement. Betty Oliver will submit a rough draft on Sunday. The purpose was stated as follows: "To form a national system of support to assist families and friends of persons with handicaps or disabilities by (a) dissemination of appropriate, current information, (b) promotion and encouragement of advocacy and monitoring efforts, and (c) development of linkage among parent groups." Recognizing the mobility of the population, we wish to serve all geographic areas as well as all disabilities.

The structure for the network will be set up on local, state, regional, and national levels. The 12 Steering Committee members will form the Board of Directors and the representatives will be known as Regional Directors. They will select one to three representatives from each state, aiming for diversity in disabilities, ages, and interests.

Saturday, April 25, 1981

In further discussion of structure, it was decided that the Board of Directors would elect its own officers. The current board will serve

for two years, after which one third of the members will be elected each year.

Membership in the network will be composed of organizations and individuals. Each organization will have one vote and their representative must be a parent. Individual members may not vote, but will be entitled to all services and publications of the network.

State representatives will be asked to:

1. Represent their state in the network
2. Be a communication link for the exchange of information
3. Provide a list of parent groups in their state
4. Serve on a committee
5. Provide the network with copies of newsletters or other forms of communication.

It was decided to form an Advisory Board of four to six persons to provide support and credibility for our organization and to foster cooperation with professionals. Members will be chosen by the Board of Directors. Patty Smith will work on a job description for advisors.

By-laws for the network will be drawn up by Marty Meyer, Susan Schill, and John Huber. It was suggested that they be simple and flexible and that the committee read other by-laws such as those of Closer Look. By-laws will be checked by an attorney and mailed to board members for approval. The name Parent Network was selected, and we will incorporate as a non-profit organization. The legality of the name will be verified at the time of incorporation.

In discussing programs, the following priorities were established, in this order: information, publicity, conference, and advocacy. Pat Koerber reported on the operation of PIRC. We will gather information from parent groups nation-wide through state and regional representatives. Newsletters will be kept on file as well as information on conferences of national interest. The development of a national directory is also a possibility. Information will be disseminated by mail or by telephone. Our own newsletter will be published four times a year.

In the area of publicity, it was felt that everyone should be committed to this effort and that specific action steps by developed for regional directors. A national publicity campaign will be tied in with our first conference. We will also develop a fact sheet, organizational chart, letterhead, and brochures.

A conference will be scheduled for Spring 1982, and Patty Smith will check on the feasibility of holding it in Omaha through the University of Nebraska. Discussion of advocacy as a part of our program and purpose was tabled until a later date.

Sources of funding were listed as follows:

1. Dues - Individual or family, $10
   Organization, $25
   Student, $5
   Sustaining, $100
   Life, $200
2. Funds generated by publicity and programs
3. Contributions
4. Private foundations
5. Government grants

Purposes for funding are to provide: programs, publicity, administrative costs, and financial support for start-up needs of local groups.

Elizabeth Campbell reported on the possibility of using PLATO, a telecommunications system with computer capacity. This system can:

1. Exchange information on a large, nationwide scale
2. Store and retrieve information
3. Provide training
4. Set up conferencing
5. Promote large scale advocacy efforts.

Since computer capacity is growing and costs are going down, Ms. Campbell suggested that we try it on a short term basis. It is possible that we can use the system for a limited time at no cost. Several board members will visit Don Bitzer at the University of Illinois to discuss further the computer and its use by the Parent Network. We visited the IUPUI Library for a short demonstration of the PLATO equipment.

At our Saturday evening session, Patty Smith further discussed a national conference. All regional directors will be expected to participate in planning, publicity, and in obtaining funding for parents to attend. The board recommended a moderate price for meals and lodging. We will plan for approximately 150 participants and 40 hotel rooms. The conference will be held from Friday evening through Sunday noon, with time provided for meetings of the Parent Network, Pilot Parents, etc. We will select a speaker of national prominence, and our Advisory Board members will be invited. A newsletter and history of the Parent Network will be distributed to those attending the conference. The following suggestions were made for possible presentations:

Developing and funding networks, coalitions and information centers
Model programs, such as Pilot Parents
Training for monitoring
Vocational training and employment
Rights and responsibilities under 94-142
Respite care
Normalization within institutions
Surrogate parents
Self-esteem, social development and competence
Communication and mobility devices
Children who are trauma victims

It was decided that the local contacts will be kept active for at least another year to assist the board in planning, decision making, and setting up of the conference.

Sunday, April 26, 1981

A copy of this report will be mailed to all those who attended last year's conference, after it has been approved by board members. By-laws will be distributed at the conference next spring. Membership fees will not be collected until by-laws, incorporation, and receipt of the IRS number are completed.

Officers for the Parent Network Board of Directors were elected and will serve a two-year tern:

President	Pat Koerber
First Vice President	Patty Smith
Second Vice President	Kook Huber
Secretary	Betsy Trombino
Treasurer	Elaine Clearfield

Elaine Clearfield will also serve as historian. Kook Huber will chair the publicity committee with assistance from Liz Campbell. Betty Oliver will chair the membership committee. Betty Hourihan and Bonnie Fairchild will be asked to lend their expertise in the area of ways and means.

The following time line was adopted:

April 27-May 15	Minutes mailed PLATO system investigated
May 16-June 5	Minutes corrected and approved Conference confirmed By-laws drafted and mailed PLATO report mailed
June 6-July 3	By-laws approved Reaction to PLATO; direction on next move
July 4-July 17	Minutes and report sent to October 1980 conference attendees Logo sent to board members
July 18-Sept. 1	Fact sheet and organizational chart developed Incorporate; consult attorney
Sept. 2-Oct. 1	File for IRS number Begin conference publicity
March 1982	National Conference

Evaluation of the network and how it operates will be based on accurate record keeping, tracking the number of requests for information, number of memberships, and feedback from users of the service.

The following description or brief purpose was adopted to accompany the name Parent Network: "The national communication system to link parents of those with special needs."

The board approved a job description for Advisory Board members:

1. To support/endorse the efforts of the Parent Network
2. To review materials presented by the Board of Directors and make comment/recommendations
3. To provide expertise in matters affecting the Parent Network
4. To participate in an annual meeting of the Parent Network

In filling the vacancies on the Board of Directors, the following recommendations were made for contacts:

Region III - Ruth Sullivan Autistic Society
Johns Hopkins Hospital
Candlelighters
Temple University

Region IV - Betty Barnes
Jan Scarborough

To conclude our meeting, the board adopted a philosophy statement:

We believe that persons with handicaps are valued, developing human beings with the potential to grow and contribute to society.

We believe that parents are the key to developing these potentials.

We believe exchange of information provides support and assistance to parents.

We believe in parents' promotion, advocacy, and monitoring efforts.

We believe the expertise unique to parents makes a valuable contribution.

We believe in a national linkage to strengthen and encourage parents.

Prepared by,

Betsy Trombino
Secretary

TOP RANKED ACTIVITIES OF AN EFFECTIVE LOCAL PARENT GROUP/PARENT COALITION

RANK	ACTIVITY
1	Provides accurate information to parents about local services for all handicapping conditions.
2	Provides parent-to-parent groups for discussions, emotional support and mutual help.
3	Publishes a newsletter several times a year that contains information on workshops, books and articles, community services, and about various disabilities.
4	Reaches out to parents who are isolated and don't know where to get help.
5	Instructs parents about their children's and their own legal rights.
6*	Acts as a clearinghouse and an informal referral source so that parents can find the most appropriate services for their child.
6*	Promotes a positive image of the handicapped person.
8**	Keeps parents up to date on laws and regulations that have an impact on persons with special needs.
8**	Has a speaker's bureau upon which other community groups can call readily.
8**	Often invites professionals to take part in its parent-oriented training sessions.
8**	Makes a special effort to inform local pediatricians of parents' need for immediate advice once a handicapping condition has been discovered.

* & ** tied rankings

TOP RANKED ACTIVITIES OF AN EFFECTIVE NATIONAL PARENT NETWORK

RANK	ACTIVITY
1	Provides a communication system to link parent groups nationally for sharing of goals, methods, successes, etc.
2	Acts as an effective parent voice, to allow clout equal to that of professional groups.
3	Makes available a national directory of referral sources on various handicapping conditions.
4*	Alerts local or statewide parent groups of the need for action on specific issues
4*	Acts as a vehicle of information exchange on innovative services in other localities and states.
6*	Provides workshops and annual conventions for parents across all handicapping conditions.
6*	Functions as a clearinghouse of funding sources that are available to local parent groups.
6*	Acts as an organized, national voice to ensure that laws such as PL 94-142 and the Rehabiliation Act of 1973 are carried out effectively.
6*	Promotes more public awareness through movies, TV, radio, magazine articles, and newspapers.
10*	Presents a unified voice of and for parents and families on a national level.

* Tied rankings

PARENT INFORMATION RESOURCE COUNCIL, INC.

222 East 70th Street
Indianapolis, Indiana 46220

An Organization for Parents - By Parents

NATIONAL CONFERENCE FOR PARENTS OF THE HANDICAPPED

October 17 - 19, 1980

PROGRAM

FRIDAY, OCTOBER 17		
4:30 p.m.	Registration - get acquainted (dinner on your own)	
6:00 p.m.	Reception in foyer	
7:00 p.m.	Conference opening Greetings - Frank Kenny Introduction - Pat Koerber	Carnegie
7:30 p.m.	Parent Panel Ruth Christ Sullivan Dorothy McNair Betty Hourihan	
9:00 p.m.	Working sessions - Parent Information Network Planning	
	Purpose (Eleanor Owen)	Carnegie I
	Structure (Betty Hourihan)	Carnegie II
	Program (Patricia McGill Smith)	Robin I
	Communication (Marty Meyer)	Robin II
	Funding (Betsy Britten)	Suite 603-605
SATURDAY, OCTOBER 18		
8:00 a.m.	Registration	
8:30 a.m.	Workshops	
	#1 Genetics: Dr. Joe Christian & Dr. Sam Rhine Sloane	
	#2 P.A.C.E.R.: Marge Goldberg	Baruch
	#3 V.I.A.: Betty Hourihan	Carnegie II
	#4 In-Home Respite Care: Betty Oliver	Carnegie I
10:00 a.m.	Coffee Break	
10:30 a.m.	Workshops	
	#5 Advocacy: Dorothy McNair & Ruth Sullivan	Carnegie II
	#6 Pilot Parent: Patricia McGill Smith	Baruch
	#7 Community Support Programs: Eleanor Owen	Carnegie I

12:00 noon	Welcome: Rodger Coleman, Office of the Mayor, Indianapolis, Indiana	
	Lunch: Barry Neil Kaufman, speaker	Morgan, Lilly
1:30 p.m.	Workshops	
	#8 Barry Neil & Suzi Kaufman	Baruch
	#9 Parent organizations: Betsy Britten	Sloane
	#10 Legal issues: David Dunlap	Carnegie I
	#11 Cancelled	
3:00 p.m.	Break	
3:15 p.m.	Workshops	
	#12 Cancelled	
	#13 Closer Look: Marie Ormsby	Sloane
	#14 Diet & Behavior: Laura Stevens	Baruch
5:00 p.m. - 6:00 p.m.	Happy Hour - Meet the Authors - Cash Bar	Foyer
6:00 p.m. - 8:00 p.m.	Dinner	
8:00 p.m. - 9:30 p.m.	Meeting of the Committee of the Whole	

SUNDAY, OCTOBER 19

9:00 a.m.	Continental breakfast	Foyer
	Introduction - Indianapolis Foundation	
9:30 a.m.	Closing session - National Parent	Carnegie
	Information Network - The Committee of the Whole	

This first national conference for parents of the handicapped has been made possible by a grant from the Indianapolis Foundation. Contributions have also been made by the Rock Island Refining Corporation, Western Electric Company, and CMW, Inc. The Western Electric Pioneers have assisted with the volunteer activities and registration. Also assisting with the volunteer effort are Pat Koerber, Parent Information Resource Center (PIRC), the PIRC Advisory Board and parents of the Parent Information Resource Council, Inc. We wish to thank all of the conference presenters who have so generously reponded to this effort.

Parent Information Resource Council, Inc., Board Members - October 1980

1. G. Elizabeth Kenny, Learning Diabilities - President
2. Beverly Purdue, Autism - Vice President
3. Alice Ryan, Cerebral Palsy - Secretary
4. Ruth Jarvis, Aphasia - Treasurer
5. Sally Baxter, Spina Bifida
6. Evelyn Froehlich, Downs Syndrome
7. Georgianna Garlock, Cerebral Palsy
8. Joan Hermeling, Learning Diabilities
9. Marty Meyer, Cerebral Allergy
10. Patricia O'Drobinak, Cerebral Palsy
11. Mary Pease, Hearing Impaired

CONFERENCE PRESENTERS

Betsy Britten, director, Southwestern Ohio Coalition for Handicapped Children (SOC) Parent Information Center, Cincinnati, Ohio. She is a board member of the Spina Bifida Association of America, member of the Closer Look Advisory Group, the State Superintendent's Council for Special Education in Ohio and the Hamilton County Regional Placement Center. Professionally she holds a teaching license and has taught in Ohio schools. As a volunteer she founded the Spina Bifida Association of Cincinnati and the Cincinnati Kindervelt and has served with the Cincinnati Center for Developmental Disorders and the Wyoming Junior Women's Club.

Paula Goldberg, co-director, P.A.C.E.R. Center, Inc. (Parent Advocacy Coalition for Educational Rights), a statewide parent training project for parents of handicapped children, Minneapolis, Minnesota. She serves on the State Council for the Handicapped Children and Youth, the Pre-School Handicapped Children's Task Force of the Governor's Council and did a study on Special Education and Children's Rights for the League of Women Voters. She is also an experienced teacher and lobbyist.

Betty Hourihan, director, V.I.A. (The Volunteer Information Agency), program housed at the South Shore Mental Health Center, Quincy, Massachusetts, which was started eight years ago to help parents of children with special needs. She has written several pamphlets: "There's Something Special About You," "Now's a Good Time for Counseling," and "God and Jimmy".

Barry Neil Kaufman, author, Son Rise, Giant Steps, et al., and director of Options, Inc., Roslyn Heights, New York.
Suzi Kaufman has played a leading role in development of the techniques the Kaufman's used with their son, Raun, that enabled him to overcome his autism.

Dorothy McNair, formerly with the Exceptional Family Advocacy Center at the University of Oregon, co-authored their Advocacy Primers. Mother of seven, including three with handicaps, and a nurse by training, she is on boards for the local Association for Retarded Citizens, Housing and Community Develpment, the Developmentally Disabled and chairperson for "Independent Environments" developing a group home for the physically handicapped. She is also involved in organizing parent groups across the state of Oregon.

Kathleen Nitsch, assistant professor and director of graduate studies, Department of Psychology, Indiana University - Purdue University at Indianapolis. From Tuscaloosa, Alabama, she earned her Ph.D. at Vanderbilt University. While there she served as editorial assistant to Dr. Nicholas Hobbs for Classification Project which resulted in three books, Issues in the Classification of Children, Vols. I & II, and Futures of Children, published by Jossey-Bass. She is a consultant to the Residential Advisory Committee, Indiana Department of Mental Health; to the Indiana State Developmental Disabilities Council and the Indiana Society for Autistic Children, and serves on the PIRC Advisory Board, and is technical advisor for this conference.

Betty Oliver, Westwego, Louisiana, organized the Association for Research in Children's Emotional Disorders and developed and received funding for its In-Home Respite Care Service. She served two years as parent coordinator for the P.T.A., has worked with and helped organize various state and local parent groups and is a member of the Huxley Institute and the National Alliance for the Mentally Ill. Her experiences as a parent appear in her book, The ABC's of Hanging on While Raising a Family with a Disturbed Child.

Marie Ormsby, project manager for Closer Look (Parents Campaign for Handicapped Children and Youth), Washington, D.C. She has a B.A. in journalism from the University of Idaho and a M.S.W. from the Graduate School of Social Work, University of Maryland. Previous experience includes operating information and referral services for the Easter Seal Society of Prince George's County, Maryland; publishing the national "Directory of Information and Referral Services." She has been with Closer Look since 1975 and researched and written many of the fact sheets, newsletter articles and other material. She is also representing Barbara Scheiber, director, the Parents Campaign for Handicapped Children and Youth, whose name appeared on the conference brochure and who regrets she is unable to be with us.

Eleanor Owen, Seattle, is president of the Washington Advocates for the Mentally Ill; board member, Washington State Mental Health Advisory Committee; founder, Western state Hospital Citizen's Guild and secretary of the National Alliance for the Mentally Ill. She is also the 1980 winner of the Jefferson Award for Outstanding Service to the Community and was a member last year of the founders panel for the National Alliance for the Mentally Ill.

Patricia McGill Smith, Parent activities counsultant for the Parent Support Counsultant Service, Meyers Children's Rehabilitation Institute. A parent of seven children including a nine-year-old daughter who has a handicap, she coordinated the regional Pilot Parents Program for the Greater Omaha Association for Retarded Citizens and established parent support groups in Kansas, Nebraska, Iowa and Missouri. As the 1979 recipient of the Rosemary F. Dybwad International Award, she visited parent support projects in Canada, England, Norway and France.

Laura J. Stevens is the author of How to Feed Your Hyperactive Child and How to Improve Your Child's Behavior Through Diet, both using her experiences as a parent. With a Masters Degree in political science from the University of Cincinnati, she is currently teaching computer science at Purdue University, West Lafayette, Indiana.

Ruth Christ Sullivan, director, the Autism Services Center, Huntington, West Virginia. A parent and a professional in the field of autism for over 15 years, she is a two-term past president and honarary board member of the National Society for Autistic Children, founder of NASAC's Information and Referral Service and author of the 1974 and 1978 editions of the U.S. Facilities and Programs for Children with Severe Mental Illnesses (for the National Institute of Mental Health). She is current editor of the "Parents Speak" section of the Journal of Autism and Developmental Disorders and has published numerous articles, bibliographies, book and film reviews.

Joe C. Christian, a native of Oklahoma, did his undergraduate work at Oklahoma State University. He received Ph.D. and M.D. degrees from the University of Kentucky and had his internship and residency at Vanderbilt University, Nashville, Tennessee. He is now professor and chairman of the Department of Medical Genetics and director of the Indiana Statewide Genetic Disease Program.

David Dunlap comes from Battle Creek, Michigan and graduated from the University of Michigan. Graduate work was at Georgetown University and his legal education at Indiana University in Indianapolis. Besides being an attorney, he has taught adult reading, been a mental health planner and human service program administrator. He was a planner with the Indiana Protection and Advocacy Task Force and its first attorney. He is now in private practice with an Indianapolis law firm.

Sam Rhine, is a teacher and geneticist at the Marion County Association for Retarded Citizens in Indianapolis. In the last two years he has spoken to 165 high schools and 80,000 students about the causes and prevention of mental retardation and birth defects.

PARENT INFORMATION RESOURCE COUNCIL, INC.
222 East 70th Street
Indianapolis, Indiana 46220

An Organization for Parents - By Parents

The Parent Information Resource Council, Inc., is a cross-disability organization of parents and professionals sharing information on available services and current activities affecting the handicapped and their families. In our mobile society, we have found a universal thirst for sharing information among aware parents which crosses geographical boundaries and diagnostic labels.

Thanks to a grant awarded us by The Indianapolis Foundation, we are planning the first such Conference for Parents of the Handicapped or Disabled. With splendid cooperation from interested community leaders, the conference will be held in Indianapolis in the fall of 1980 - The International Year of the Family. One main objective of the conference will be to develop the beginning of a National Parent Information Network.

Like you, we have had the stimulating experience of meeting parents around the country. We hope to acquaint families from different areas with each other, to discuss issues of mutual interest and to consider ways for parents nationwide to stay in communication. We are seeking your input during this initial planning stage as we want guidance from a broad spectrum of involved persons and organizations concerning topics and speakers.

We ask that you examine the enclosed brochure and send your recommendations to us right away, along with the number of additional brochures you can distribute to your contacts for their suggestions. To insure full representation from all geographic and disability interests, attendance must be by invitation; but we will accommodate as many as our resources will permit.

Sincerely,

G. Elizabeth Kenny

G. Elizabeth Kenny
PIRC, Inc. - Conference Planning Committee

Name_____

Address_____

City_____

State_____ ZIP_____

Phone_____

Please mail_____ Conference Brochures for our distribution

For your planning purposes, please allow _____ Conference invitations for us.

Announces
the
INVITATIONAL CONFERENCE for PARENTS of the Handicapped or Disabled

As parents of children with special needs, we know that communication with other parents eases the task of meeting the present and future needs of our children. We have come to understand that, although our children's specific handicaps do differ, our parental concerns are basically the same.

We recognize that having a child with a handicap automatically places parents in a minority group facing special challenges. Often, it is PARENTS who inspire successful problem-solving approaches.

Through Parent Groups...

...**You** play the vital role of influencing bureaucracies
...**You** earned the right for parent participation in program decisions
...**You** encourage dialogue between parent and professional
...**You** provide "extra hands" for other parents & professionals
...**You** create programs—where there were **no** programs

As Individual Parents...

...**You** provide Parent Leadership
...**You** volunteer your services and your talents
...**You** write books and papers to benefit others
...**You** strengthen other families through Parent-to-Parent support
...**You** are the Head of Your Family
...**You** are "Where it begins"

At this point, the Parent Information Resource Council, Inc. is planning the **INVITATIONAL PARENT CONFERENCE** that will be held in Indianapolis in the fall of 1980—**The Year of the Family**.

This conference is taking much brainstorming and input from parent leadership across the country. In this, the planning stage, IMMEDIATE communication is vital, as a means to share information and to identify parents who have made outstanding contributions from various geographic areas, socio-economic levels, cultural groups and disability interests.

We are seeking your help, at this time, so that we may develop the most meaningful format and topics with broad interest.

Share your desires, knowledge and recommendations for the **first**...

INVITATIONAL CONFERENCE for PARENTS of the Handicapped or Disabled

RESPONSES & INQUIRIES TO:

Parent Information Resource Council, Inc.
INVITATIONAL PARENT CONFERENCE
1363 East 38th Street
Indianapolis, Indiana 46205

Telephone Answering Service:
(317) 926-4142

and The Year of the Family

Parent Information Resource Council, Inc.
INVITATIONAL PARENT CONFERENCE
1363 East 38th Street
Indianapolis, Indiana 46205

Dear Planning Committee—

___I am a parent/guardian of a handicapped or disabled child/adult.

___I am **NOT** a parent/guardian, but offer my assistance as indicated below (or attached).

___I would like to receive an **INVITATION** to attend the Conference.

___I would like to **PARTICIPATE** as: ( ) a representative of _____; ( ) a Worker at the Conference; ( ) a Speaker on the topic of _____; ( ) Financial help; ( ) Other _____

___I would like to **RECOMMEND**: ( ) Materials to share (please send samples); ( ) Workshop on the topic of _____; ( ) The name of an excellent Speaker in the area of _____ (please supply all appropriate information).

BE SURE TO COMPLETE OTHER SIDE BEFORE MAILING

(continued from other side)

____Attached are names, addresses and phone numbers of parents or parent groups you should contact, as they have been effective in improving the quality of life for our handicapped and/or the families.

____Other recommendations are attached on a separate sheet.

My area of special interest is _____

MY NAME _____ Phone Bus. 1-( )-_____
Res. 1-( )-_____

ADDRESS _____ CITY & STATE _____ ZIP _____

FEEL FREE TO USE ADDITIONAL SPACE

---

learning disabled
mental retardation
sensory handicaps
speech/language
spina bifida
others

autism
behavioral disorder
cerebral palsy
epilepsy
growth disturbance
health related disability

Help us plan this event!

The Parent Information Resource Council, Inc. encourages and advances the efforts of parents of handicapped children by sharing information on current activities of parental interest.

We are a voluntary, not-for-profit corporation supported through membership fees and subscriptions to "NEWSCENE" which is edited and published by our Parent Editorial Board. Contributions are tax exempt.

Our membership maintains a Parent Library, provides speakers upon request and gives endless hours of volunteer work for various groups, agencies and organizations. We learn from one another, and NOW the **first**...

INVITATIONAL CONFERENCE for
PARENTS of the Handicapped or Disabled
coming in
The Year of the Family
1980

Parent Information Resource Council, Inc.
INVITATIONAL PARENT CONFERENCE
222 E. 70th. Street
Indianapolis, Indiana 46220

Nonprofit Org.
U. S. Postage
PAID
Indianapolis, IN.
Permit 5234

INVITATIONAL CONFERENCE for PARENTS
of the Handicapped or Disabled